

MEETING SUMMARY

Advisory Committee to the Texas Cancer Registry (ACTCR)
Thursday, December 13, 2018
Austin, Texas

Members/Designees/Guests Participating:

Kelly Willis Merriman, M.P.H., Ph.D., C.T.R., University of Texas M.D. Anderson Cancer Center, **ACTCR Chair**

Maria Hoang Tran, M.P.H., C.T.R., Memorial Hermann Healthcare System, **ACTCR Vice-Chair/Chair-Elect**

Amanda English, M.P.H., C.P.H., C.H.E.S., American Cancer Society
Nimisha Bhakta, M.P.H, Texas Department of State Health Services
Theresa Byrd, D.Ph., R.N., Texas Tech University Health Science Center
Harem El-Serag, M.D., M.P.H., Baylor College of Medicine
Sharon Giordano, M.D., M.P.H., University of Texas M.D. Anderson Cancer Center
Daikwon Han, Ph.D., Texas A&M University Health Sciences Center
Zuber Mulla, Ph.D., M.S.P.H., Texas Tech University Health Sciences Center El Paso
Sandi L. Pruitt, Ph.D., University of Texas Southwestern Medical Center
Michael Scheurer, Ph.D., M.P.H., Baylor College of Medicine
Sanjay Shete, Ph.D., University of Texas M.D. Anderson Cancer Center
Elaine Symanski, Ph.D., University of Texas Health Science Center at Houston
Kristina W Whitworth, Ph.D., M.S.P.H., University of Texas Health Science Center at

Texas Cancer Registry (TCR)/Other DSHS Staff Present:

Melanie Williams, Ph.D., Branch Manager, Texas Cancer Registry (TCR) Paige Miller-Gianturco, Ph.D., Epidemiology Manager, TCR Katie Dahlquist, M.Ed., Information Specialist, TCR Keisha Musonda, M.P.H., Epidemiologist, TCR

Note: Please refer to the ACTCR webpage for handouts and presentations from the meeting (see links under December 2018: http://www.dshs.texas.gov/tcr/actcr.aspx)

- I. Welcome—Kelly Willis Merriman, M.P.H., Ph.D., C.T.R., ACTCR Chair
 - a. Dr. Merriman called meeting to order.
 - b. Dr. Merriman introduced three new ACTCR members: Amanda English, M.P.H., C.P.H., C.H.E.S., American Cancer Society; Nimisha Bhakta, M.P.H., Texas Department of State Health Services; and Harem El-Serag, M.D., M.P.H., Baylor College of Medicine.



- c. Dr. Merriman announced transition to New Chair, Maria Hoang Tran, M.P.H., C.T.R., in 2019.
- d. Dr. Merriman announced the new Vice-Chair/Chair-Elect will be Philip Lupo, Ph.D., M.P.H., starting in 2019.
- e. Members approved the minutes from the April 20, 2018 meeting.
- II. General Update and Group Discussion—Melanie Williams, Ph.D., TCR Branch Manager
 - a. Dr. Williams reviewed the status of action items from the April 2018 ACTCR meeting.
 - 1. TCR job postings are being shared with ACTCR members during monthly updates.
 - 2. TCR maintained same level of CDC grant funding. A third of TCR budget is provided by CDC NPCR grant; the other two-thirds is provided by CPRIT legislative funding.
 - 3. TCR received North American Association of Central Cancer Registries Gold Certification.
 - 4. TCR has been sharing information about new data products in monthly ACTCR updates.
 - 5. TCR will likely have the opportunity to apply for SEER Registry status in 2019.
 - 6. TCR revised patient contact study materials to make guidelines clearer for researchers. No policy changes needed to be made.
 - b. Dr. Williams provided an update on TCR staffing.
 - 1. TCR currently has 53 full-time employee positions. Keeping positions filled continues to be an issue.
 - 2. Dwenda Smith, C.T.R., is retiring at the end of the month. She is currently the program supervisor for the Northwest Texas Registry Operations Group.
 - 3. John Arend, M.P.H., TCR epidemiologist, has accepted the director position with Colorado Central Cancer Registry. This is his last week with TCR.
 - 4. Keisha Musonda, M.P.H., is a new epidemiologist who will be working with IRB requests. Keisha introduced herself and provided a summary of her past work experience.

ACTION ITEM: Open positions will be shared in monthly **ACTCR** updates.

c. Dr. Williams said that TCR will request funding for same work as the past year via the Centers for Disease Control and Prevention – National Program of Cancer Registries (CDC-NPCR) non-competitive grant application. While TCR will request more funds, grant application will be considered successful if we maintain current funding level.

ACTION ITEM: Updates on grant funding will be shared in monthly ACTCR update when available.



- d. Dr. Williams provided an update on 86th Legislative Session topics.
 - 1. Proposed public and research linked Texas Health Care Information Council (THCIC) In-Patient and Out-Patient Data Sets was discussed. State THCIC law doesn't allow it to occur. Bill will need to be introduced in the legislative session that would allow for linkages.
 - 2. Amanda English (ACS) stated that if proposed CPRIT legislation is passed, a request for more CPRIT funding will be on the November 2019 statewide ballot.

ACTION ITEM: Updates from 86th Legislative Session will be included in monthly ACTCR updates.

e. Dr. Williams announced that data for 1995-2016 diagnosis year in November. Based on TCR estimations, we think she will maintain Gold Certification. Data for 2017 diagnosis year will be submitted for preliminary evaluation in January 2019.

ACTION ITEM: Data submission and certification status will be shared in monthly ACTCR updates when available.

f. Dr. Williams shared information about the DSHS Data Sharing Workgroup. TCR data are the most requested, and TCR has the most IRB studies. Legal analysis is being done for all DSHS areas sharing data, including TCR. The analysis will identify barriers to sharing data with the appropriate entities.

III. Member Request Topics—Group Discussion

- a. Dr. Miller-Gianturco provided an update on TCR data products published in 2018 and proposed products for 2019.
 - 1. See handout TCR Data Products May–December 2018 for list, links and description of products published since last ACTCR meeting.
 - 2. See handout 2019 TCR Data Dissemination Plan for a snapshot of products proposed for 2019.
 - 3. Dr. Merriman suggested a product looking at HIV-associated cancers.
 - 4. Ms. English suggested a product looking at lung cancer and low-dose CT scan for early detection.
 - 5. Dr. Williams asked if there is value in having one or two printed publications vs electronic only. Consensus that a couple of printed publications are good for sharing with lawmakers and policy staff.

ACTION ITEM: Dr. Williams will reach out to CPRIT to see if they foresee any specific data request needs based on research proposals.

ACTION ITEM: ACTCR members can suggest new data products as needed.

- b. Dr. Miller-Gianturco provided an update on patient contact studies.
 - 1. TCR revised patient contact study materials. No policy changes needed to be made. See handout Patient Contact Study Updates for

- description of changes made to Guidelines and supporting documents.
- 2. Dr. Miller-Gianturco provided overview of how TCR flags deceased patients in the TCR database so their information isn't provided to researchers. TCR is linked with Social Security Death Index monthly.
- 3. Dr. Merriman asked if a hospital can share their own Do Not Contact list with TCR so patients who have said they don't want to be contacted can be flagged. Dr. Miller-Gianturco and Dr. Williams said that TCR will honor Do Not Contact requests received from hospitals.
- c. SEER Registry Application
 - 1. Dr. Williams provided more information on potential application for SEER Registry status in 2019. See handout SEER Proposal Timeline Dec 2018 for task areas and proposed timeframe.
 - 2. TCR will likely need the most help in task areas 6-8. TCR will also need to decide if we need to move to a different reporting model.
 - 3. Most data items required by SEER are now required by CDC and Commission on Cancer.

ACTION ITEM: Dr. Williams will lead a workgroup with subset of ACTCR members to help with task areas. Workgroup will possibly meet once a month.

- d. Dr. Williams provided an update on TCR's Cancer Registry Software Assessment Report.
 - 1. See handout SEER Proposal Timeline Dec 2018 for more information. (Names of states that participated in assessment survey have been redacted from the report.)
 - 2. SEER*DMS was the clear winner.
- IV. Member Updates/New Business—Group Discussion
 - a. Member Updates
 - 1. Dr. Merriman stated that MD Anderson has hired nine new registry staff.
 - 2. Theresa Byrd shared that the Graduate School of Biomedical Sciences at Texas Tech University received accreditation from the Council on Education for Public Health.
 - b. Proposed 2019 meeting schedule
 - 1. Ms. Dahlquist proposed that ACTCR meet in person in April 2019 and via conference call in October 2019.

ACTION ITEM: Poll to set dates for April and October meetings will be sent in January 2019.

V. Adjourn